

FASD: Knot Alone

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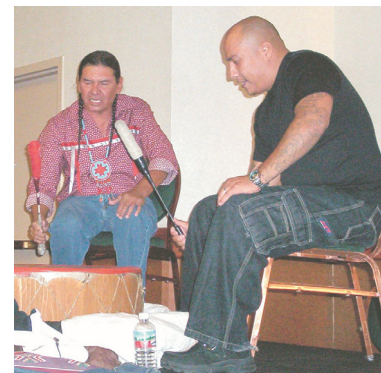
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Women in Recovery: Second Summit Highlights Native Spirit

Native Americans believe that the entire community is responsible for the next seven generations. Thus, preventing FASD is crucial to a healthy future. To address the needs of Native women in alcohol recovery, the FASD Center for Excellence convened its second women in recovery summit June 29 and 30. Held in Phoenix, the event drew about 300 participants from across the State of Arizona. The National Organization on Fetal Alcohol Syndrome (NOFAS) hosted the meeting. The mostly Native American audience included women in recovery, treatment providers, policymakers, and government representatives. Concerns about addressing FASD and alcohol abuse in tribal communities were highlighted throughout the summit. The meeting also incorporated traditional Native American ceremonies, drumming, and song.



American Indian Drum Group

The first day taught women in recovery and treatment center staff about the effects of prenatal alcohol exposure and the needs of children with FASD. Day 2 brought State policymakers together with tribal leaders and Indian Health Service officials to learn about FASD and its impact in Arizona. The summit also included a town hall meeting where women in treatment shared their stories with policymakers and government representatives.

Kathleen Tavenner Mitchell, NOFAS vice president and spokesperson, explained NOFAS's role in addressing FASD, especially its mission of education, training, and advocacy. She also shared her story of recovery and her experiences as the birth mother of a daughter with FAS. Ms. Mitchell stressed that women can recover from addiction. They need help dealing with codependency, developing new communication skills, changing belief systems, and discovering their spirituality.

Ms. Mitchell later chaired a powerful panel discussion by "warrior moms"—birth mothers of children with FASD. The women's accounts revealed common threads: a family history of alcoholism, the difficult path toward recovery, the discovery that their children had FASD, and their commitment to

improving their children's lives. Their words were filled not only with regret but also with understanding, clarity, and a sense of reconciliation. Together, the women communicated a sense of hope for the future.



Birth mother panel

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Second Women in Recovery Summit

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A second panel, composed of adoptive mothers, grandparents, and fathers, shared very personal accounts of the challenges and joys of raising children with FASD.

Recurring themes included the lack of knowledge of FASD in the school system, concerns about who will care for their children after they are gone, and the need for respite.

In addition to personal stories, experts shared information about alcohol and women. FASD specialist Candace Shelton noted that alcoholism among women is a tremendous public health problem in the United States. Women account for one-third of those who abuse or are dependent on alcohol. Nearly 5 million women have alcohol problems, and women account for 25 percent of clients in treatment.

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Young women who drink report higher rates of alcohol-related problems than older women, such as abuse and rape. However, the incidence of alcohol dependence is greatest among middle-aged women. Women who are single, divorced, or separated also are more likely to have drinking problems, as are women who are depressed or have a history of sexual abuse.

Ms. Shelton explained why women who use alcohol get drunk faster than men. They metabolize alcohol differently, resulting in a higher concentration of alcohol in the blood. Gender differences also affect treatment. Most treatment models were developed for male clients. The model does not address barriers that women often struggle with.

Ardyce Turner, Children's Services Specialist, State of Alaska Office of Children's Services, spoke about the brain damage associated with FASD. She described her experiences as the birth mother of a son with fetal alcohol syndrome (FAS). She shared the difficulties her son has and the types of behaviors seen in persons with FASD.

Another speaker, Suzanne L.B. Kuerschner, is a child development specialist who focuses on fetal alcohol syndrome (FAS) and related neurodevelopmental disorders. In her experience, tribal and government services can work together to develop powerful prevention and intervention models. She introduced the idea of building circles of collaborative care that reflect the Native American belief that the entire community is responsible for the next seven generations. For example, providers need to understand the family's concerns, and parents and teachers should be taught how to tailor strategies to help children with FASD learn.

Ms. Kuerschner also stressed the need to shape FASD State systems to ensure culturally competent services and to reflect the community's needs and strengths. A community task force with broad representation can facilitate training, develop prevention and early intervention materials, identify community-based sites for activities, and set policies and procedures.

The need for State systems is critical given the high cost of FASD. Rick Harwood, an economist, noted that across the United States, FAS cost about \$5.4 billion in 2003 and about \$100 million in Arizona. The lifetime costs can be as high \$4.2 million for the most severely affected individuals. If one takes into account quality of life issues, FAS prevention may be cost-effective at up to \$850,000 per child.

Teresa Kellerman, director of the FAS Community Resource Center, moderated a panel discussion on FASD in Arizona with service providers and agency staff. The panelists reported on efforts to build integrated systems of care to address FASD, as well as their experiences with FASD prevention, identification, and support services in Arizona. Ms. Kellerman cited statistics that, of 85,000 babies born in Arizona this year, 850 will have FASD. However, only four cases of FAS were reported to the State. She also reported that Arizona has taken some steps to curb alcohol use by pregnant women. For example, State law requires signs to be posted where alcohol is sold or served, warning that alcohol can cause birth defects.



Dear Dan



I'm looking for information on the role nutrition plays in the treatment of FASD. Have any studies been done looking at this subject?

Atkins Shmatkins, Just Help the Kids

Dear Atkins:

There is a lot of enthusiasm on the part of some individuals for nutritional approaches to treat numerous problems. However, nothing has been tested in any kind of controlled manner with infants or children with FASD. In addition, many studies that have been done in this area have been open studies in which everyone knows who is getting what kind of treatment. These types of studies can produce a “placebo effect,” in which people who think the treatment will cause improvement perceive improvement. Although the placebo effect is helpful for many individuals, it makes it difficult to show clearly whether a certain treatment actually works.

Some nutritional interventions do seem to work in some individuals. For example, if someone has a deficit of certain vitamins or minerals, adjusting the levels of these vitamins or minerals can help reduce symptoms that often look like psychiatric disorders. However, very large doses can be dangerous. In some individuals, a deficit in magnesium can cause symptoms that look like attention deficit disorder. If the levels of magnesium are brought within normal range, the symptoms decrease. If the levels of magnesium are too high, the symptoms get worse.

Years ago, megavitamin therapy was recommended. There is now concern about overdoses of several vitamins, so the recommendation is typically that normal levels be maintained. Some persons have difficulty processing these substances and may need higher or lower than normal doses to maintain normal levels.

You may have heard of the gluten-free casein-free (GFCF) diet or the Feingold diet. These are diets where certain foods need to be eliminated. They typically need to be followed 100 percent to see whether they work. They seem to work with a limited group of individuals but have not been proven effective in controlled studies. That group of individuals tends to be one whose bodies are intolerant of certain substances. For example, in some children increased sugars increase hyperactive behavior, while other children have no response.

Everything is very individual. *Any thoughts of changing diets, such as adding vitamins, minerals, or fatty acids, should only be done in consultation with a physician.* Nothing should be done with infant diets without first consulting a physician. With FASD, it is important to rule out any possible medical reason for negative behaviors and find a physician willing to discuss this issue. That might mean running some tests to determine what to do. Then the physician can review interventions to try and which ones are the safest to try first.

This suggestion also applies to the use of substances often thought of as safe, such as herbs. Many substances can help but many can harm certain individuals. More research is needed to test these nutritional approaches in some kind of controlled way so that we can more definitively say what works with whom.

Have a question for Dan?

E-mail fascenter@samhsa.gov and include “Dear Dan” in the subject line. Letters may be edited for content and space. Please indicate whether you want your name and State published.



Guest Editorial: Life With Fetal Alcohol Syndrome

Rob Wybrecht

I was diagnosed with fetal alcohol syndrome (FAS) at birth and adopted by my parents when I was 11 months old. I am now 31 years old.

Living with FAS has been difficult at times. Special challenges for me in school were math and writing. I could not think and write at the same time, and I could not listen and write at the same time. Writing took my total concentration. Essay questions took too much effort, too much writing. I could do better talking into a tape recorder. I needed to tape record lectures, as I could not take notes.

Middle school was especially hard because my locker was way over by the gym and my classes were on the other side of school. Also, my schedule was changed three times during the first week of school. My parents tried to help me learn my schedule before school started, but with all the changes, it did not help.

There were two things that I remember helped me. In high school, one teacher would always write down when we had a test, in red on the chalkboard. The quizzes would be in blue and the homework was in white. I also was allowed to have one textbook at school and one that I could take home to write in and highlight important things.

I think this Chinese proverb explains how I learn. I found it when I was in seventh grade and showed it to my mother. It is still true.

Tell me, I will forget.

Show me, I may remember.

Involve me, I will understand.

I think this proverb also influenced my choice of classes and jobs. In my senior year of high school, I took a culinary arts class. I was so involved in the class that

at the end of the year I got the outstanding senior of the year award.

One job I had was working in a restaurant for 4 years. Vocational rehabilitation helped by explaining my

disability to my supervisor. I had two bosses there, but unfortunately, they both quit at the same time. So I called vocational rehab to help me explain my disability to my new boss. However, because I had been successful in my job before, my case had been closed. By the time my case was reopened, I had lost my job.

One recent job I had was difficult for me because my boss didn't understand that I had a disability. She didn't seem to want to work with the job coach. It also seemed impossible for the job coach to make any sort of contact with her when there was a problem.

I now have a job as a church custodian. My job coach helped me to create a checklist of things I have to do during the day. The job coach took a map of the church and sat down with me to find out what was the first thing I needed to do each day and where it is. My job takes me in a complete circle of the building, and we created a little color-coded binder with laminated sheets that tells me what things I need to do for that day. I have a dry erase marker that I use to check things off. Before I had only a one-page checklist with everything on it, and I would get ahead of myself and not complete something that should have been done before.

If I were applying for a job today these are some things I would want a new boss to know about me:

- I can be easily distracted.
- I have trouble remembering verbal instructions. It helps if things are written down.



Rob Wybrecht

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- I have trouble remembering several tasks or a task with several parts.
- Sometimes I try to do too many things at once and find myself not finishing what I start.
- I sometimes have trouble pacing my work.
- It helps if I can work alongside someone or if someone can share the work with me.

My strengths are:

- I am very reliable, dependable, and punctual.
- I am creative.
- I am always willing to help others.

Three years ago, my parents and I moved from the home I had lived in for 28 years to a new home near my sister and her family. My parents are getting older, and my sister and brother-in-law said that they would be there to support me when my parents passed away. I was very reluctant and stubborn when it came time to move. The transition was difficult for me. I had to find a new job and new support people. Now I am more used to it.

I live with my parents because I need help with organization, paying bills, keeping a home clean, and keeping myself safe. I would like some kind of supervised independent living, but it doesn't exist. There are no group homes for people like me with an average IQ. I write a monthly check to my parents for shared expenses. I also have a joint checking account with my mom's name on it.

My parents and my sister help keep me safe. They make sure they know where I am, and I call home if I'm going to be late. I help out around the house by gardening, mowing the lawn, and doing some of the cooking. My specialty is Hawaiian chicken. I also cook macaroni and cheese for my sister's kids. They love it.

I waited until I was 21 before I got my driver's license because I was afraid the car in front of me would do something quick, and I wouldn't have time to react. I also have my own car, and I drive to work and to other activities. I saved my money for years to buy the car, and my family helped me pick it out and helps me to maintain it. I took special driver's education classes for people with disabilities.

I try to avoid spots that I know have a lot of traffic, and I have never had an accident or gotten a ticket.

I have a friend whom I met almost 3 years ago. She and I were working on the committee for a camp conference for people who have FASD. She lives in a group home nearby. It is a good friendship. We do things like go to the movies, the mall, and the park. I also keep in touch with other people I met at the camp conference as well as other conferences. Usually this is by e-mail. Sometimes I go to the movies with people from work. I also love computer games, and I like to look at a Web site that uses a camera to show trains going by.

Some of the ways I have been helping spread the message about FASD is by speaking at conferences and through my bumper stickers. They say, "When you're pregnant, the best drink is no drink at all." I was giving them out at conferences on FASD, but when I ran out I had trouble getting more. So I found a printing company to make them for me, and I sell them at cost and use the money that I make to buy more. I also helped make a video called "Students Like Me," to help elementary school teachers understand FASD.

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Local Communities and State RFPs Released

The FASD Center for Excellence released a request for proposals for community organizations to incorporate FASD into service delivery. More than 60 proposals were received. The Center also released an RFP for States to develop FASD systems of care and received 23 proposals.





I have learned to cope with my disability, but I don't want you to be at peace with FASD. I need you to make changes to help children and teens as well as other adults. These are some of the things I want you to try and change. I would like everyone to understand FASD. I would like every child to be able to get a diagnosis early, like I did. I would like to help show teachers ways to help students like me. Ask students what might help them. I also would like for employers to understand what might make the job easier for people with FASD.

I have learned to cope with my disability, but I don't want you to be at peace with FASD.

NOTE: This editorial is composed of excerpts from Rob's remarks at the second Building FASD State Systems meeting, held in Kissimmee, Florida, on May 5-6, 2004, and from a conversation with Rob and his mother, Barb Wybrecht, about what it's like to live with FASD.

Editorial Guide

We welcome your thoughts on newsletter topics and other issues. E-mail fascenter@samhsa.gov and include "FASD Center newsletter" in the subject line. Or write to FASD Center Newsletter Editor, 1700 Research Boulevard, Suite 400, Rockville, MD 20850. Include your name, city, and State. Unless otherwise requested, letters may be published with the author's name and location. Letters may be edited for space and content.

I've Been Searching So Long...

Looking for information on FASD? Research articles, materials for a meeting, maybe a really good video? Check out the FASD Center Web site, fascenter.samhsa.gov, and visit the Information Resource Center. Our database has nearly 5,000 entries. If you still need help, our Information Specialist is available 9-6 Eastern time, or leave a message.

On the Road Again: FASD Center Training Update

Vacation? What's that? FASD Center staff have had a busy spring and summer traveling across the country to train families and professionals. Nearly 900 people participated in FASD Center training sessions, including:

- Service providers
- Parents and families
- Educators
- Public defenders and other justice professionals
- Substance abuse professionals
- Native American youth leaders and advisors
- Adoption groups
- Mental health professionals and social workers
- Federal and State government personnel

Topics varied, with nearly 400 participants in FASD 101 alone. Other sessions included the FASD Center, FASD in the Criminal Justice System, Socialization Coaching, Co-Occurring Disorders, Motivational Interviewing, Identifying Women at Risk, and FASD in Families. Staff conducted training in:

- Alaska (August)
- Arizona (June)
- California (June)
- Delaware (April, July)
- District of Columbia (April)
- Florida (May)
- Iowa (June)
- Maryland (April)
- Minnesota (July)
- Missouri (August)
- Texas (June, August)
- West Virginia (April)

Want to know more? Contact our Information Resource Center at 866-STOP-FAS (786-7327), e-mail fascenter@samhsa.gov, or complete the Training/Technical Assistance Request Form on our Web site, fascenter.samhsa.gov/misc/ttaintro.cfm.



Upcoming Events

On the FAS Track to Understanding: A National Conference on Fetal Alcohol Spectrum and Related Neurobehavioral Disorders, October 28-29, 2004, Riverside, California

For more information, contact Jim Stream or Eva Carner, 888-818-6298, or visit www.calfas.org.

FASAWARE UK Full Day Workshop, November 10, 2004, Skelmersdale, Lancashire, England. For more information, contact FASAWARE UK, 01942-223780, e-mail fasawareuk@blueyonder.co.uk, or visit www.fasaware.co.uk.

Connecting FASD Voices, November 18, 2004, Edmonton, Canada. For more information, contact Lisa Clauson-McIntosh, 780-477-1999, ext. 227.

Demystifying Fetal Alcohol Spectrum Disorder, November 29, 2004, Oshawa, Canada. For more information, contact Sheila Burns, 905-427-8862, ext. 346, or e-mail sburns@rfecdurham.com.

FASD International Francophone Conference, December 9-10, 2004, Quebec, Canada. For more information, contact SAFERA, 866-ASAFERA (272-3372), e-mail info@safera.qc.ca, or visit www.safera.qc.ca.

National Conference-Fetal Alcohol Spectrum Disorder: Equality of Access: Rights and the Right Thing To Do, February 24-26, 2005, British Columbia, Canada. For more information, contact UBC Interprofessional Continuing Education, 604-822-0054, e-mail ipconf@interchange.ubc.ca, or visit www.interprofessional.ubc.ca.



**Juvenile Justice RFP Released:
View it at www.fasdcenter.com/rfp.**

**If you're pregnant, don't drink.
If you drink, don't get pregnant.**

For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.



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